

University of Groningen

Psychological adjustment of parents of pediatric cancer patients revisited

Wijnberg-Williams, BJ; Kamps, WA; Klip, EC; Hoekstra-Weebers, JEHM

Published in:
Psycho-oncology

DOI:
[10.1002/pon.927](https://doi.org/10.1002/pon.927)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2006

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Wijnberg-Williams, BJ., Kamps, WA., Klip, EC., & Hoekstra-Weebers, JEHM. (2006). Psychological adjustment of parents of pediatric cancer patients revisited: Five years later. *Psycho-oncology*, 15(1), 1-8. <https://doi.org/10.1002/pon.927>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

PSYCHOLOGICAL ADJUSTMENT OF PARENTS OF PEDIATRIC CANCER PATIENTS REVISITED: FIVE YEARS LATER

BARBARA J. WIJNBORG-WILLIAMS^{a,*}, WILLEM A. KAMPS^b, ED C. KLIP^a
and JOSETTE E.H.M. HOEKSTRA-WEEBERS^{a,c}

^a *Psychosocial Services, University Medical Center Groningen, The Netherlands*

^b *Beatrix Children's Hospital, Division of Pediatric Oncology, University Medical Center Groningen, The Netherlands*

^c *Comprehensive Cancer Center North Netherlands, Groningen, The Netherlands*

SUMMARY

We investigated the psychological functioning of parents of children suffering from pediatric cancer using a prospective design over a five-year time period. Parents of children diagnosed with cancer participated at diagnosis (T1), six months (T2), twelve months (T3), and five years later (T4, $n = 115$). Repeated measures ANOVAs were calculated for the three measures of psychological distress (GHQ, SCL-90 and STAI-S) to examine changes over time and gender differences. Independent *T*-tests were computed to examine differences between the mean scores of the parents at T4 and the norm groups. The effects of health status and earlier levels of distress on T4 functioning were examined using ANOVA and partial correlational analysis. Results showed that levels of reported distress, psychoneurotic symptoms and state anxiety significantly decreased across time to normal levels at T4 except on the GHQ. A significantly higher percentage of parents (27%) than in the norm group (15%) showed clinically elevated scores on the GHQ. Mothers had higher scores than fathers only on state anxiety. Parents of relapsed children reported higher anxiety levels than parents of surviving and deceased children. Psychological functioning at T1 was significantly related to functioning at T4. These results support the conclusion that although parental distress decreases with time, a significant number of parents still suffer from clinical distress after five years. Parents of relapsed children are at risk for long-term psychological problems as are those with higher levels of psychosomatic complaints at diagnosis. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS: pediatric cancer; parental stress; gender differences; risk factors; prospective longitudinal design, oncology

INTRODUCTION

Understanding the aspects of human functioning that affect the way people deal with major life events can help health care professionals tailor their interventions to the needs of patients suffering from life threatening diseases. Specifically, attention has increasingly been directed towards the way individuals cope with major stresses and daily hassles (most often based on Lazarus and Folkman's, 1984 theoretical model of stress,

appraisal and coping) in the hope of identifying (risk) factors that contribute to the development of mental health problems. Much recent research has focussed on identifying the psychosocial factors that may help identify individuals who are at risk for developing problems in dealing with the day to day struggles they are confronted with when forced to deal with life threatening diseases (Wallander and Varni, 1998). In the field of cancer research, a major concern is the way families cope with the distress pediatric cancer causes in the light of rising survival rates (already around 70%) (Dockerty *et al.*, 2000; Kazak *et al.*, 2003).

Research has shown that parents of children diagnosed with cancer initially report higher levels of emotional distress and more psychosomatic

*Correspondence to: Psychosocial Services, University Medical Center Groningen, P.O. Box 30.001, Groningen 9700 RB, The Netherlands. E-mail: B.J.Wijnberg@psb.umcg.nl

complaints than norm populations (Sawyer *et al.*, 2000; Dahlquist *et al.*, 1996; Hoekstra-Weebers *et al.*, 1998; Kazak *et al.*, 2003). Prospective studies on adjustment over a range of 1–10 years post-diagnosis found parents of long term survivors as a group to adjust well over the years following diagnosis (Kupst *et al.*, 1995; Dahlquist *et al.*, 1996; Hoekstra-Weebers *et al.*, 1998). However, an estimated 25–33% of the parents continue to suffer from problems (Kupst *et al.*, 1995; Hoekstra-Weebers *et al.*, 1999; Kazak *et al.*, 2003). Posttraumatic stress symptoms in parents, especially mothers, of long-term survivors have been reported (Brown *et al.*, 2003; Kazak *et al.*, 1998).

In general, men and women differ in the degree to which they report distress and psychological symptoms. Women report higher rates of non-specific distress, anxiety and depression (classed as affective and anxiety disorders), men report higher rates of antisocial behaviour and drug/alcohol problems (classed as antisocial personality and substance abuse dependence disorders) regardless of other socio-demographic factors (Koeter and Ormel, 1991; Simon, 2002). Simon (2002) suggests that gender differences found in the adult population reflect differences in manner of expression and not necessarily in quantity. These general differences may reflect the social role differences between the two sexes in the general population. Taking these findings on the general population into consideration, one would expect to see a high level of distress (neurotic and depressive symptoms) in both parents of children diagnosed with cancer whereby mothers would be expected to report more distress than fathers. Contrary to this expectation, reports have been inconsistent on gender differences in parents' self-reports of stress and diverse psychological symptoms as a result of the diagnosis and treatment of cancer in their children (Dockerty *et al.*, 2000; Hoekstra-Weebers *et al.*, 1998; Kupst *et al.*, 1995). Some studies report higher levels of distress in mothers (Speechley and Noh, 1992; Grootenhuis and Last, 1997) while others report similar levels of distress for both mothers and fathers (Goldbeck, 2001; Hoekstra-Weebers *et al.*, 1998).

Specific attention has been paid to the effect of stress on the psychological well-being of parents in conjunction with the health status of their children showing that parents of children who suffered a relapse reported more psychological problems than parents of children who were doing well (Grootenhuis and Last, 1997; Hoekstra-Weebers

et al., 1991; Kupst *et al.*, 1995; Dahlquist *et al.*, 1996; Kazak *et al.*, 2003; Sawyer *et al.*, 2000). In addition, when considering the psychological functioning of parents whose children have died, a comprehensive review of parental bereavement (Dijkstra and Stroebe, 1998) supports the notion that the distress of bereaved parents also decreases with time. Few prospective studies published to date have included data obtained from parents whose child has died from cancer or considered the effects of 'survivorship' on parental distress (Kupst and Schulman, 1988).

The aims of this study are to examine the change in self-reported distress in parents of children with cancer over time, and to explore the possible differences between fathers and mothers in reported distress. We will also report on the effect of the child's health status on the amount of distress experienced by the parents at T4 and the possible effect of initial distress at T1 on distress at T4.

METHOD

Participants

All 164 parents who initially participated shortly after diagnosis (T1), including those who were not approached six months (T2) or twelve months later (T3) because their child had recently died from cancer (Hoekstra-Weebers *et al.*, 1998), were eligible to participate in the final measurement five years later (T4). Six parents could not be located and three were deceased leaving 155 parents for potential participation. Of these, 115 parents agreed to participate (response rate of 74%).

The respondents at T4 could be classified in the following manner: Thirty-six parents had children who died as a consequence of their cancer and 119 were parents of surviving children. Twenty-one of the 36 parents of deceased children participated at T4 (response rate of 58%) while 15 parents either refused to participate because they expected participation to cause too much emotional strain ($n = 12$) or they did not react at all ($n = 3$). Ninety-four of the 119 parents of surviving children participated (response rate of 79%). Twenty-five of the 119 parents of surviving children declined to participate at T4 either because they sought closure, they found the confrontation to be too emotional or their child had a recent relapse of the illness. Therefore, in

total, 115 parents participated at the five-year follow-up (response rate of 74% of the potential 155 respondents).

Comparison of the participants with non-participants on demographic variables at the five year follow-up (T4) showed a significantly higher participation level from surviving children's parents than from deceased children's parents at T4 (chi-square = 6.16, $p < 0.05$). Also, more parents of older children who participated at T1 declined to participate at T4 (t -test = -2.50, $p < 0.05$). The mean age of T4 non-participant's children at diagnosis was 6.3 (S.D. = 4.6), for participant's children this was 5.7 (S.D. = 4.6) years. The mean level of education in the group of participating parents was higher than the level of the parents who did not participate at T4 (t -test 2.47, $p < 0.05$). No significant differences were found between the group of participants and the non-participants at T4 on: gender of either parents or children; age of the parents; or marital status. Both the medical diagnosis and prognosis of the children at T1 had no significant effect on the decision to participate in the study at the 5-year follow-up (T4). Mean ages of parents and children as well as other demographic and illness-related characteristics are presented in Table 1.

Procedure

During a period of 27 months, the parents of all newly diagnosed children with cancer in the Groningen University Medical Center, Beatrix Children's Hospital, Division of Pediatric Oncology were invited to participate in this study. The parents of children with a life expectancy shorter than six months and the parents who spoke insufficient Dutch were not asked to participate.

The pediatric oncologist first informed parents about the study and provided written information. They were subsequently asked to participate by the researcher. Informed consent as required by the medical ethics committee of the hospital was obtained. Participants completed questionnaires within 14 days from the time of diagnosis (T1), at 6 months (T2), 12 months (T3) and five years later (T4). Fathers and mothers were instructed to complete questionnaires separately. T1 assessment took place in the hospital. All other questionnaires were completed at home and mailed to the hospital.

Table 1. Demographic characteristics of the sample at T1 and T4

Variable	T1		T4	
	N	%	N	%
Gender parent				
Male	79	48.2	57	49.6
Female	85	51.8	58	50.4
Age parent				
<30	22	13.4	15	13.0
30–35	48	29.3	33	28.7
35–40	58	35.4	43	37.4
>40	36	22.0	24	20.9
Marital status				
Married/cohabitation	158	96.3	109	94.8
Widowed	1	0.6	1	0.9
Divorced	5	3.0	5	4.3
Education				
Lower	61	37.5	37	32.2
Middle	79	48.2	58	50.4
Higher	24	14.6	20	17.4
Gender child				
Male	57	65.5	41	67.2
Female	30	34.5	20	32.8
Age child				
<4	35	40.2	29	47.5
4–8	16	18.4	7	11.5
8–12	20	23.0	16	26.2
>12	16	18.4	9	14.8
Diagnosis				
Leukemia's	35	40.3	23	37.6
Brain Tumors	10	11.5	4	6.6
Mal. lymphoma's	14	16.1	9	14.8
Wilm's tumor	8	9.2	7	11.5
Sarcoma's				
Soft tissue	9	10.3	8	13.1
Bone	2	2.3	1	1.6
Neuroblastoma	4	4.6	4	6.6
Germ cell tumor	3	3.4	3	4.9
Hepatoblastoma	2	2.3	2	3.3
Prognosis (T1)				
>75%	35	40.2		
25–75%	39	44.8		
<25%	13	14.9		
Child's health status (T4)				
Deceased			11	18.0
Relapsed			5	8.2
Long term survival			45	73.8

Instruments

The following instruments were used to assess psychological functioning of the parents:

The 12-item version of the General Health Questionnaire (Goldberg and Williams, 1988), a self-report measure of psychological symptoms commonly used for screening, was used in this study as a general measure for psychological distress. The scores range from 0 to 12. The psychometrical properties of the scale as used in the Dutch population are reported to be highly satisfactory (Koeter and Ormel, 1991). The alpha values in this study ranged from 0.86 to 0.91 for the various measurement points. A conservative cut-off score of 3 with this version of the GHQ for indication of clinically elevated levels was advised (Koeter and Ormel, 1991). Persons who score 3 or higher are considered more likely to be in need of psychological or psychiatric help. The Dutch manual provides information on the norm group (a representative randomly selected community group of 1580 men and 1655 women, age range 18–65) as well as information on the reliability and validity of this instrument (Koeter and Ormel, 1991). Norm values are reported for the total group of respondents but not for women and men separately.

The Symptom Checklist (SCL-90, Derogatis, 1977) was included as a second measure. The SCL-90 is a self-report, 90-item questionnaire that measures the presence of psychosomatic symptomatology. The respondent indicates the presence of complaints for eight classes of psychosomatic symptoms on a five-point scale ranging from 'not at all' to 'extreme'. This study reports on the total score for psycho-neuroticism. The Dutch manual provides separate norms for men and women in the general population (Arrindell and Ettema, 2003). The norm group consisted of 1184 men and 1184 women as a representative random sample taken from the general Dutch adult population according to current consensus statistics on age (age range 20–65) and level of education. The alpha values in this study ranged from 0.96 to 0.97 for the various measurement points.

The State-Trait Anxiety Inventory (STAI-S, Spielberger, 1983), state version, measures the transitory emotional condition of stress (or tension) perceived by the respondents. Dutch norm group data and information for men and women separately on both reliability and validity are available (Ploeg, 2000). The reference group

consists of a representative random sample (men: $n = 188$, women: $n = 201$, age range 16–70) from the general population of Leiden, a relatively large city in the Netherlands (Ploeg, 2000). The alpha values in this study ranged from 0.94 to 0.96.

Analysis

Repeated measures ANOVAs were calculated for three measures of psychological distress (GHQ, SCL-90 and STAI-S) to examine the effects of time and gender on the self-reports of the 96 respondents who participated at all four measurement points. Independent *T*-tests were computed to examine differences between the mean scores of the 115 participating parents at T4 and the norm groups on these three measures. At T4 ANOVA was computed to examine differences between parents of children who were surviving ($n = 86$), had a relapse ($n = 8$) or had died ($n = 21$) followed by *post hoc* Scheffé Tests when appropriate. Partial correlation coefficients (control variable: child health status) were calculated in order to examine the effects of T1, T2 and T3 scores on T4 scores. Correlation coefficients between the number of days since the death of the child and the parents' scores on the three measures for psychological distress were calculated to explore the effect of the passage of time on the scores of the deceased children's parents ($n = 21$). Correlation coefficients of <0.30 indicate a weak relationship, those between 0.30 and 0.50 a moderately strong relationship and >0.50 indicate a strong relationship (Cohen, 1988).

RESULTS

Repeated measures analysis of variance on the scores of the 96 parents who participated at all four measurement points indicated a significant within subjects main effect showing a decrease in reported psychological distress (GHQ), psychosomatic complaints (SCL-90) and state anxiety (STAI-S) across time. A significant gender difference was found only for the STAI-S indicating that mothers reported more state anxiety than fathers (Table 2). No significant interaction effects were found although a trend was found for the STAI-S indicating that the anxiety of mothers decreased more rapidly than that of fathers.

Table 2. Descriptives of the study measures from T1 to T4 across time and gender

		Norm data		T1		T2		T3		T4		ANOVA	
		<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>M</i>	(S.D.)	<i>F</i>	<i>p</i>
GHQ	(f)	Total		6.2	(3.1)	3.9	(3.3)	2.7	(3.4)	1.4	(2.4)	Time:	68.70 <0.001
	(m)	1.1	(1.2)	6.8	(2.9)	4.9	(3.9)	3.0	(3.7)	1.9	(2.7)	Sex:	1.56 0.22
												Interaction:	0.26 n.s.
SCL-90	(f)	117.2	(27.3)	128.8	(40.5)	123.1	(37.0)	117.2	(36.0)	112.6	(24.0)	Time:	9.89 <0.001
	(m)	128.9	(36.4)	137.2	(26.9)	129.2	(30.0)	125.7	(35.4)	123.3	(33.3)	Sex:	2.07 0.153
												Interaction:	0.20 n.s.
STAI-S	(f)	37.3	(10.3)	43.1	(10.3)	41.1	(10.0)	38.2	(11.0)	35.5	(8.9)	Time:	37.91 <0.001
	(m)	39.4	(11.2)	50.5	(10.4)	45.7	(11.7)	41.2	(11.4)	37.9	(9.8)	Sex:	6.36 <0.01
												Interaction:	2.46 0.06

(f)=fathers ($n=46$), (m)=mothers ($n=50$), GHQ=General Health Questionnaire, SCL-90=Symptom Checklist, STAI-S = State-Trait Anxiety Inventory-State, T1= measurement point at diagnosis, T2=measurement point 6 months after diagnosis, T3=measurement point 12 months after diagnosis, T4=measurement point 5 years after diagnosis.

Table 3. Analysis of variance, means and standard deviations at five years (T4)

Measures	Parents of surviving children ($n=86$)		Parents of relapsed children ($n=8$)		Parents of deceased children ($n=21$)		ANOVA	
	Mean	S.D.	Mean	S.D.	Mean	S.D.	<i>F</i>	<i>p</i>
GHQ	1.4	2.4	3.5	4.3	2.0	2.3	2.91	$p=0.059$
SCL-90	116.8	29.8	127.3	26.8	121.3	30.5	0.55	$p=0.58$
STAI-S	35.3	9.1	41.5	11.3	39.9	8.8	3.33	$p=0.039$

GHQ=General Health Questionnaire; SCL=Symptom Checklist (SCL-90); STAI-S=State Trait Anxiety Inventory-State.

Comparison of the 115 T4 participant's mean scores on the GHQ at T4 with the norm group mean showed that parents reported a higher overall level of psychological distress than the norm group ($t = -2.198$, $p = 0.03$). Twenty-seven percent of the parents reported scores at T4 that fell in the clinically elevated range ($n = 30$, $m = 5.2$, S.D. = 12.4, 95% confidence interval: lower bound: 4.32; upper bound: 6.08) as compared with 15% in the norm group ($X^2 = 10.51$, $p = 0.001$). Comparison of the mean scores on the SCL-90 and the STAI-S at T4 with the means from the norm groups showed no significant difference with the norm group means for either fathers or mothers (SCL-90 for fathers: $t = 0.631$, $p = 0.53$; SCL-90 for mothers: $t = -0.042$, $p = 0.97$; STAI-S for fathers: $t = 1.19$, $p = 0.24$; STAI-S for mothers $t = 0.939$, $p = 0.35$).

ANOVA on the GHQ at T4 showed a near-significant group effect of health status of the

children ($F = 2.91$, $p = 0.059$). No significant group effect was found on the SCL-90 at T4 ($F = 0.55$, $p = 0.58$) though a significant group effect was found for state anxiety (STAI-S, $F = 3.33$, $p = 0.039$) (Table 3). *Post hoc* Scheffé test on the GHQ showed that parents of relapsed children tended to report the most distress ($p = 0.054$). Scheffé tests on the STAI-S did not indicate that one group of parents suffered more anxiety than the remaining groups of parents.

In addition, clinically elevated scores on the GHQ were found for 23% ($n = 20$) of the parents of surviving children, 50% ($n = 4$) of those with relapsed children and 29% ($n = 6$) of the parents of deceased children.

Because the size of the groups of parents of relapsed and deceased children was small, we also compared the means of the three groups according to a non-parametric measure (Mann-Whitney-*U*). No significant differences were found for the GHQ or the SCL-90. Pairwise comparisons of group

Table 4. Partial correlations between scores at T1,T2, T3 with T4 for both fathers and mothers controlling for health status of the child (surviving, relapsed, dead)

Measures	Diagnosis Fathers		Diagnosis Mothers		6 months Fathers		6 months Mothers		1 year Fathers		1 year Mothers	
	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>
GHQ	0.30	0.03	0.18	0.18	0.55	0.000	0.32	0.02	0.38	0.009	0.44	0.002
SCL-90	0.41	0.002	0.58	<0.000	0.62	0.000	0.69	0.000	0.54	0.000	0.75	0.000
STAI-S	0.37	0.04	0.44	0.001	0.58	0.000	0.64	0.000	0.57	0.000	0.63	0.000

GHQ = General Health Questionnaire; SCL-90 = Symptom Checklist; STAI-S = State Trait Anxiety Inventory-State.

means on the STAI-S yielded the following results: a significant difference appeared between parents of surviving children and parents of children who were deceased on the STAI-S ($U = 614.50$, $p = 0.023$) indicating a higher level of anxiety in parents of deceased children. Furthermore, a trend towards significance between the mean scores of parents of surviving and relapsed children on the STAI-S was found ($U = 217.00$, $p = 0.085$).

In order to explore the effect of the passage of time on the scores of the deceased children's parents ($n = 21$) we calculated correlation coefficients between the number of days since the death of the child and the parents' scores on the three measures for psychological distress (range 439–1804 days, mean = 1281, S.D. = 470). The correlations of 'time' with scores on all three measures were not significant ($n = 21$; GHQ: $r = -0.20$; SCL-90: $r = -0.37$; STAI-S: $r = -0.22$). However, the correlation did show a moderate link between the passage of time since the death of the child and the number of complaints reported on the psychoneuroticism scale of the SCL-90 at T4.

Correlations (partialled for health status of the child) between measures for parental distress, psychological complaints and anxiety at diagnosis (T1), 6 months (T2), 12 months (T3) and five years later (T4) are presented in Table 4. The correlations of fathers' scores on the GHQ (measure for distress) at the last (T4) with all other measurement points were significant. The correlations between the fathers' scores at all measurement points on the SCL-90 (measure for psychological complaints) showed a significant moderately strong relationship. The correlations of the fathers' scores on the STAI-S (measure for anxiety) were also significant. The strength of the correlations on all three measures varied in the same manner: diagnosis (T1) with T4 was weakest; the 1 year measurement point (T3) with T4 was

somewhat stronger and the correlation of the scores at the 6 month measurement point (T2) with T4 was the strongest.

For mothers, the correlation between the scores five years later (T4) and diagnosis (T1) were significant for the SCL-90 (strong) and the STAI-S (moderate) but not for the GHQ. The correlations between T2 measurements and T4 measurements were significant for the SCL-90 and the STAI-S, and the correlations between the scores on all three measures at T3 with the T4 measurement was significant. The GHQ correlations were strongest between the 6 month and five years measurement points T1 with T4, followed by T3 with T4 and then T1 with T4. On the SCL-90 (psychological complaints) the scores at T3 correlated the strongest with T4 scores, followed by T2 with T4 and then T1 with T4. For the STAI-S (anxiety) the strongest correlations were between T2 and T4 followed by T3 with T4 and then T1 with T4.

DISCUSSION

This study is fairly unique in its prospective longitudinal design in which the subjects provided the same type of information using the same self-report measures at different time points across a five-year period. In the first place, this study shows a significant decrease in levels of psychological distress, psychological complaints and state anxiety reported across time for both mothers and fathers on all three of the self-report measures we employed. This finding is consistent with the results other prospective longitudinal studies have reported to date (Dahlquist *et al.*, 1996; Kupst *et al.*, 1995; Sawyer *et al.*, 2000). However, the participants in this study on the whole still showed elevated levels of psychological distress five years after diagnosis

on the GHQ as compared to the norm group. In fact, a significantly larger percentage of the parents (27%) reported clinically elevated levels of distress on the GHQ five years after initial diagnosis at 'case' status level as compared to the 15% reported in the norm group population (Koeter and Ormel, 1991). This gives an indication that some individual parents were still struggling with the cancer experience five years later.

When comparing fathers and mothers, we found a significant gender effect across time on the STAI-S showing a higher overall level of anxiety in mothers than in fathers across time. This is consistent with our expectations based on the literature on gender differences leading to the hypothesis that mothers would report more anxiety, distress and complaints than fathers (Simon, 2002). Surprisingly, no significant differences between mothers and fathers on the GHQ and SCL-90 were found. Apparently, the gender difference is a bit more complicated. On a speculative note, it is conceivable that the relatively high levels of initial distress fathers report as well as the relatively strong association between fathers scores at T1 on their scores at T4 could be responsible for this finding.

In addition, although no significant relationships between the child's expected chance for survival and parental stress was found up to one year after diagnosis (Hoekstra-Weebers *et al.*, 1998), health status of the child at 5 years after diagnosis is related to the reported parental stress level at that time. Parents of relapsed children reported higher levels of state anxiety and tend to report more general distress than parents of children who were surviving disease free or had died from their cancer. Also, a trend in the direction of more stress reported by parents of relapsed children on the GHQ was found. This is hardly surprising considering their circumstances. Even though all parents indicate they retain a certain amount of fear for their children's health, these parents must continue to deal with the increased uncertainty of whether their child will survive the cancer (Grootenhuis and Last, 1997). These results should be viewed with extreme caution as the numbers of respondents in the deceased ($n = 21$) and relapsed groups ($n = 8$) are very small. Future research could focus on the possible differences in parental stress that arise from change of dealing with the continuing illness (relapse) of their child to dealing with the loss of a child. It is plausible that parents who continue to

experience more distress during the illness phase could be prone to experiencing extreme difficulties during the grieving process.

Significant relationships were found between the end scores (T4—five years later) and scores at diagnosis, 6 months and 12 months on all three measures for both fathers and mothers. The variation in predictive value runs from very limited (only 3% of the total variance on the GHQ for mothers at diagnosis) to a moderately high value (56% of the total variance on the SCL-90 for mothers at 1 after diagnosis). Fathers' scores fall in between the two above-mentioned extremes. These results suggest that measures of psychological functioning shortly after diagnosis had only a moderate to limited predictive value for estimating the psychological distress of fathers and mothers five years later. A pattern emerged in which the information on psychological functioning gathered at the time point of around 6 months following diagnosis (T2) provided the best predictors for the experience of psychological problems later on.

On a cautionary note, one limitation of this study that needs to be addressed in this context is the fact that a rather large time gap exists between the third and the last measurement point (4 years). Although the parents were requested to answer the questionnaires in relation to their children, unrelated life events may have had an impact on the scores at 5 years.

This study shows that psychological functioning of parents after five years is largely comparable to that of adults in the general population. However, a relatively high number of parents continue to be distressed at clinically elevated levels. We looked at the gender of the parents, the health status of the children and distress at time of diagnosis as potential predictors of later psychological disturbance. We found gender to be a less than adequate predictor of distress. The health status of the children provided some grounds for predicting problems and the predictive value of distress at the time of diagnosis is of small to moderate worth five years after diagnosis. When considering the longitudinal aspects of this study, the best measurement point for predicting psychological distress on a correlational basis was that of six months after diagnosis when treatment was well underway.

Further prospective study of psychosocial risk factors in families of pediatric oncology patients can help identify the indicators of continuing distress in families and help target them for psychosocial interventions aimed at promoting

adjustment (Kazak *et al.*, 2003). In addition to the screening proposed by Kazak *et al.*, we may need to pay more attention to the course of the coping process during treatment in order to acquire a clear view of psychosocial outcomes.

ACKNOWLEDGEMENTS

This research was funded by the Pediatric Oncology Foundation Groningen.

REFERENCES

- Arrindell WA, Ettema JHM. 2003. *SCL-90: Handleiding bij een multi-dimensionele psychopathologie indicator*. Swets & Zeitlinger: Lisse; 1986.
- Brown RT, Madan-Swain A, Lambert R. 2003. Post-traumatic stress symptoms in adolescent survivors of childhood cancer. *J Trauma Stress* **16**: 309–318.
- Cohen J. 1988. *Statistical Power Analysis for the Behavioral Sciences* (rev. edn). Lawrence Erlbaum Associates: Hillsdale, NJ, UK.
- Dahlquist LM, Czyzewski DI, Jones CL. 1996. Parents of children with cancer: A longitudinal study of emotional distress, coping style, and marital adjustment two and twenty months after diagnosis. *J Pediatr Psychol* **21**: 541–554.
- Derogatis LR. 1977. *SCL-90. Administration, Scoring and Procedures Manual-I For the Revised Version and Other Instruments of the Psychopathology Rating Scales Series*. Clinical Psychometrics Research Unit, Johns Hopkins University School of Medicine: Baltimore.
- Dijkstra IC, Stroebe MS. 1998. The impact of a child's death on parent: A myth (not yet disproved?). *J Fam Stud* **4**: 159–185.
- Dockerty JD, Williams SM, McGee R, Skegg DCG. 2000. Impact of childhood cancer on the mental health of parents. *Med Pediatr Oncol* **35**: 475–483.
- Eiser C, Hill JJ, Vance YH. 2000. Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in pediatric psychology. *J Pediatr Psychol* **25**: 449–460.
- Goldbeck L. 2001. Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology* **10**: 325–335.
- Goldberg DP, Williams P. 1988. *A User's Guide to the General Health Questionnaire*. NFER-NELSON: Berkshire, UK.
- Grootenhuis MA, Last BF. 1997. Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology* **6**: 115–128.
- Hoekstra-Weebers JEHM, Littlewood JL, Boon CMJ, Postma A, Humphrey GB. 1991. A comparison of parental coping styles following the death of adolescent and preadolescent children. *Death Stud* **15**: 565–575.
- Hoekstra-Weebers JE, Jaspers JP, Kamps WA, Klip EC. 1998. Gender differences in psychological adaptation and coping in parents of pediatric cancer patients. *Psycho-Oncology* **7**: 26–36.
- Hoekstra-Weebers JE, Jaspers JP, Kamps WA, Klip EC. 1999. Risk factors for psychological maladjustment of parents of children with cancer. *J Am Acad Child Adolesc Psychiatry* **38**: 1526–1535.
- Kazak AE, Cant C, Jensen MM, McSherry M, Rourke MT, Hwang W, Alderfer MA, Beele D, Simms S, Lange BJ. 2003. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed oncology patients. *J Clin Oncol* **21**: 3220–3225.
- Kazak AE, Stuber ML, Barakat LP, Meeske K, Guthrie D, Meadows AT. 1998. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *J Am Acad Child Adolesc Psychiatry* **37**: 823–831.
- Koeter MWJ, Ormel J. 1991. *General Health Questionnaire. Dutch Manual*. Swets & Zeitlinger: Lisse.
- Kupst MJ, Natta MB, Richardson CC, Schulman JL, Lavigne JV, Das L. 1995. Family coping with pediatric leukemia: Ten years after treatment. *J Pediatr Psychol* **20**: 601–617.
- Kupst MJ, Schulman JL. 1988. Long-term coping with pediatric leukemia: A six year follow-up study. *J Pediatr Psychol* **13**: 7–22.
- Lazarus RS, Folkman S. 1984. *Stress, Appraisal and Coping*. Springer: New York.
- Ploeg HM. 2000. *Handleiding bij de zelfbeoordelingsvragenlijst, ZBV. Een nederlandse bewerking van de Spielberger State-Trait-Anxiety Inventory*. Swets Test Publishers: Lisse.
- Sawyer M, Antoniou G, Toogood I, Rice M, Baghurst P. 2000. Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *J Pediatr Hematol Oncol* **22**: 214–220.
- Simon R. 2002. Revisiting the relationships among gender, marital status and mental health. *Am J Sociol* **107**: 1065–1096.
- Sloper P. 2000. Predictors of distress in parents of children with cancer: A prospective study. *J Pediatr Psychol* **25**: 79–91.
- Speechley KN, Noh S. 1992. Surviving childhood cancer, social support and parents' psychological adjustment. *J Pediatr Psychol* **17**: 15–31.
- Spielberger CD. 1983. *Manual for the State-Trait Anxiety Inventory*. Consulting Psychologists Press: Palo Alto, CA.
- Wallander JL, Varni JW. 1998. Effects of pediatric chronic physical disorders on child and family adjustment. *J Child Psychol Psychiatry* **39**: 29–46.